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ABSTRACT

Persons with fetal alcohol syndrome (FAS) may be diagnosed at birth based on specific symptoms and anomalies. These are history of prenatal alcohol exposure, mental retardation, central nervous system dysfunctions, growth deficiency, particular physical anomalies, and speech and language anomalies. With aging, cranial and skeletal anomalies become more pronounced. FAS adolescents and adults exhibit deficits in interpersonal relationships, immature social skills, confusing and nonproductive communication, poor daily living skills, and attention deficits. Easily influenced and excessively friendly, FAS persons are often exploited. No one documented to date has been capable of living a fully independent life. Adolescents may display inappropriate sexual behavior; isolation; loneliness; depression; and inappropriate expectations for work, school, and independence. FAS adolescents and adults have many unmet needs: adequate sheltered living and work experiences for all (not just the mentally retarded); realistic goals and expectations; structure in every aspect of life; respite care for caretakers; individual and family counseling and support groups; lifelong case management that encompasses legal and financial issues, academic and vocational training, occupational counseling and guidance, and psychosocial and developmental evaluation; and FAS inservice education for professionals. American Indians have a higher incidence of FAS than other populations. Tribes must develop community strategies for prevention or face the death of Indian Country. (SV)

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Fetal Alcohol Syndrome in Adolescents and Adults

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Fetal Alcohol Syndrome in Adolescents and Adults

The documentation of similar patterns of malformations or anomalies in babies born to mothers who used alcohol during pregnancy opened a new field in alcohol treatment. These babies were called Fetal Alcohol Syndrome (FAS) (Jones 1973). These children have a grave and disabling condition with lifelong consequences to the individuals, the families, and the community. Unfortunately many of these individuals grow to adolescence and adulthood without preventative and intervention programs. There is a great need for educational opportunities, sheltered living and structured work environments. This requires case management over an individual's entire lifetime (May 1982, 83). There is much information available on children who have been diagnosed F.A.S., however little is known about adolescents and adults. This problem has been acknowledged since ancient warnings to women not to drink while pregnant. Now that FAS can be identified it seems to be more prevalent than imagined.

F.A.S. individuals may be diagnosed at birth based on specific definitions of symptoms and anomalies. There is a poor prognosis for major improvement. Some infants function on a higher level, and they do not display enough criteria for a full diagnosis of F.A.S. They are called Fetal

Alcohol Effects (Sokel 1981). F.A.E. occurs twice as frequently as F.A.S.

There are six characteristics of Fetal Alcohol Syndrome:

1) History of Prenatal Alcohol Exposure
2) Mental Retardation: Scores range from 20-90. The average I.Q. is 68 for F.A.S. F.A.E. scores may be low or as high as 105 and above. It is impossible to predict adolescent and adult functioning, however scores do not tend to increase over time.
3) Other Central Nervous System Dysfunctions: These include neurological abnormalities, developmental delay, and structural anomalies (especially microcephalus). Infants display tremors, poor muscle tone, disruptive sleep-wake cycles, "failure to thrive," poor fine and gross motor control, hyperactivity, attentional deficits, and developmental delay.
4) Growth Deficiency: Prenatal onset continues after birth. As children they fall below the third to tenth percentiles for weight and length. After puberty some appear plump due to changes in fat distribution on their short statures.
5) Particular Pattern of Physical Malformation: These subdivisions include cranial anomalies and

skeletal anomalies. Identifying patterns of facial characteristics may occur individually or in groups. Microcephaly is included here as an observable anomaly. Others are short palpebral fissures under the eyes; flat midface at cheeks; indistinct philtrum between the nose and the upper lip; thin upper lip; micrognathia (chin); short nose; minor ear anomalies such as "railroad tracks;" low nasal bridge; epicanthal folds at inner corners of the eye.

Skeletal anomalies such as scoliosis; pectus excavatum (indentation of chest); congenital hip dislocation; limited movement of fingers, elbows, wrists; altered palmar crease patterns in hands; small nails on hands or toes; short fifth finger and birth marks. Dental anomalies in secondary teeth occur becoming more pronounced with age. Dental anomalies include malalignment and malformation. Heart problems are seen in about one third of those diagnosed but are seen less frequently in adolescents and adults. These heart problems include enlarged lateral ventricles (Kavale 1986).

6) Speech and Language Anomalies: Often is diagnosed as part of central nervous system dysfunction,

> these anomalies are so important and pronounced that they deserve symptomatology in their own right. Reading age reaches an average of 4th grade, spelling 3rd grade, arithmetic 2nd grade. General adaptive functioning average 7 years 5 months for a 16 year 5 month chronological age. A common characteristic is the speed and amount of verbal output. Upon examining this there is little or no content. There is little or no pragmatic intent, no memory for related syllables or sentences. These individuals suffer from chronic ear infections.

Broad problems are hard to address. There are no governmental services for those with IQs over 70. Forty two percent are left out unless they are labeled "Learning Disabled." Almost no one becomes fully self sufficient. Most are cared for by persons other than their natural mother. A high percentage of biological mothers are deceased by the time the individual reaches adolescence. After adulthood most wander from one living situation to another. Communication between agencies and social service, legal, and health professionals about the needs of these individuals is poor (Streissguth 1988).

Adolescents and adults with F.A.S. come in a wide variety of shapes and sizes. Microcephy and shortness of

stature are the most differentiating growth parameters. Abnormalities of the philtrum (area between the nose and upper lip), teeth, lips, nose, and eyes are common physical identifiers. The facial features often take on a coarse appearance with age. The nose and chin become prominent. Skeletal anomalies also become more pronounced with age.

Adolescents and adults share some common behavioral characteristics. There are deficits in interpersonal relationship with immature social skills. Communication is confusing and nonproductive. Daily living skills are non existent or sporadic. Sexuality is often misused and naive attitudes leave individuals open to exploitation and misuse. Physical abilities remain behind the norm in most instances, at least to some degree. Overall adaptive behavior is reflective of children's ability. These individuals do not catch up as they get older. Attention does not exceed more than five minutes. Language deficits prevent relating of experiences and emotions. Completion of multiple step tasks is impossible. There is an absence of long term goals. They talk too much, too quickly, and have little to say. They demand to be the center of attention, interrupting others with irrelevant comments. There is often perseveration and echolalia in speech and in writing. Many talk or ask repetitive questions when no one is around. Articulation problems are present within a wide range of possibilities.

Voices may be loud, deep, or unusual sounding. Because of the verbal output others expect them to be more cognitively or behaviorally competent than they are. They are impulsive and lack inhibition. They have little sense of personal space and many are "touchers." Easily influenced by others and being excessively friendly they are often exploited as they do not adequately comprehend dangerous situations. No one documented to date has been capable of living a fully independent life.

Adolescents and adults are often happy in disposition but most suffer from periodic depression and may be suicidal. Those with higher IQs are aware of their peculiarity and suffer great pressures in growing up. Streissguth sees the major changes from childhood to adolescence as being 1) Increasing inappropriate sexual behavior, 2) Isolation, 3) Loneliness, 4) Depression, 5) Inappropriate expectations for work, school, and independence, 6) Prolonged patterning or experience in dysfunctional alcoholic families.

All family members in alcoholic families suffer stress. Feelings are not often shared and there is a sense of loneliness. Often there is physical or sexual abuse. Parents model erratic immature behavior. Children often are responsible for providing physical and emotional care for parents reversing nurturing roles. If children remain in this situation as they get older many tend to also drink with

negative results in their lives. They struggle to maintain control, or at least the appearance of control. Females demand more dominant roles and need to control interpersonal relationships. Feelings are hard to identify and express. On a continuum others are either distrusted or trusted to an unrealistic extent. Upon becoming adults, children from this environment often continue to feel guilty for the emotions and behaviors of others. They often become workaholics. As adults they have difficulty establishing interpersonal relationships. They suffer from loneliness, lingering guilt, unrealistic grief and loss, are often depressed and feel worthless (Wilson 1990). All of this is difficult for individuals who function in the normal range. It is compounded for those who suffer the physical results of parental alcoholism in F.A.S.

Impaired cognitive performance, hyperactivity and minimal brain dysfunction in childhood have been linked with the later development of alcoholism. When the family has a history of alcoholism there are lower test scores by the children in neuropsychological abstract reasoning, problem solving, and perceptual motor skills. There may be a genetic vulnerability to alcoholism which may be expressed in part as a cerebral dysfunction. This may be functionally manifested as learning disabilities, F.A.E. or F.A.S., which persists into adulthood (Rhodes 1990).

Even though there are a wide range of abilities and a wide range of problems for Fetal Alcohol Syndrome adolescents and adults, there are many factors and needs which remain the same. Most are not being met.

1) There is a need for adequate sheltered living and work experiences for all, not just those whose IQ qualifies them for Mental Retardation services. There are services needed beyond those available for the Learning Disabilities labels. If these are not provided these individuals lead transient lives, are unemployed most of the time, feel lonely, isolated, worthless, and risk depression, alcohol and drug abuse, sexual promiscuity, and victimization.

2) Set realistic goals and expectations in developing programs for individuals. Wilson (1990) says that allowing the individual to make some choices and decisions encourages control feelings in that individual.

3) Structure every aspect of the individual's life. Expectations should be clear and consistent and behavioral consequences should be well defined. The level of functioning and the age of the individual must be considered but even higher level F.A.S. persons have behavioral deficits which need structure. Time should be monitored and filled with a regular routine. Physical parameters need to be defined. Tasks should be defined simply. Athletics, clubs, and other free time activities should be available on a

regular basis. Free time may also be filled by developing cultural traditions, practices, crafts, religion, and community involvement. This is satisfying to the individual on many levels. Utilize individual strengths but remember attention deficits in scheduling.

4) Provide respite care for caretakers. Care for these individuals is an exhausting lifelong experience.

5) Provide counseling and support groups for individuals and their families. Support groups, bibliotherapy, role playing, rational emotive experiences, assertiveness, biofeedback, social training, job skills, self esteem, and life skills are all areas individuals and often their families need help with (Wilson 1990; May 1982, 1983). F.A.S. ividuals often have normal reactions to their abnormal circumstances experienced in an abnormal body.

6) Case management should be lifelong. These individuals may be diagnosed at any time in their lives. The category of F.A.E. and F.A.S. is relatively new but many older adults have the syndrome in one way or another. In case management communication must be set up between all agencies and programs which the individual is involved with. This may include professional help in education, vocation, financial, psycho-social, or physical areas. It is important to consider legal inclusion in case management for two reasons. First, court advocates should be appointed for many of these

individuals. There are financial considerations to be addressed as they age and possible trusts should be established. Often parents may be either deceased or involved in dysfunctional family situations. Secondly, adjudication is 220% greater for those adolescents and adults with perceptual and academic disabilities. Traynelis-Yurek (1988) says these individuals appear to be perceived differently by legal authorities. Often they are delayed in their social emotional growth. Remediation in academic education to increase life skills and vocational training helps reduce reincarceration rates for those who function at a higher level. Vocational training involves not only specific skills but assessment counseling, developmental counseling, and preplacement counseling. Occupational orientation programs are necessary on an ongoing basis, even after employment, to provide role playing and social training.

Case management should also include psychosocial and medical examinations at key stages in the lives of F.A.S. and F.A.E. individuals. May (1982, 1983) sees this as necessary for planning for the next stage and for documentation for accountability. The need for documentation of language functioning and changes should also be maintained in the case management system. Becher (1990) cautions that language presents a major problem for F.A.S. individuals. Most IQ tests rely on language for directions and there is a need

to check on non verbal ability. The Ravens Colored Progressive Matrices (RCPM) is independent of verbal instructions, has reported acceptable validity for measuring cognitive ability and correlates with other measures of intelligence. Becher also cautions that children from multiple living situations will experience difficulty in acquiring early language skills. Bilingualism and environmental deprivation also influence language development.

7) Continuous F.A.S./F.A.E. orientations and inservice programs should be available to all professionals and persons involved with these individuals. This helps them define expectations, establish guidelines, and understand and intervene in family dynamics. Concertation should be on structuring environment, vocational, and pre vocational training, as well as social and life skills (Streissguth 1988).

American Indian adolescents spend over 8 million dollars each year on alcohol and drugs (Loretto 1988). This does not include what adults spend. American Indians are hard hit by F.A.S. with a higher percentage rate of occurrence than other populations. F.A.S. seems to be self perpertuating in this group. Health costs are stop gap and astronomical on most reservations. Property damage, loss of productivity, and economic drain alone are factors which should cause concerned Native Americans to address the

problem of F.A.S. and alcohol abuse on their own reservations. The human misery of broken homes, unemployment, totally dependent individuals, loss of self esteem, and diminishing hope for the future must be studied and dealt with (Kavale 1986).

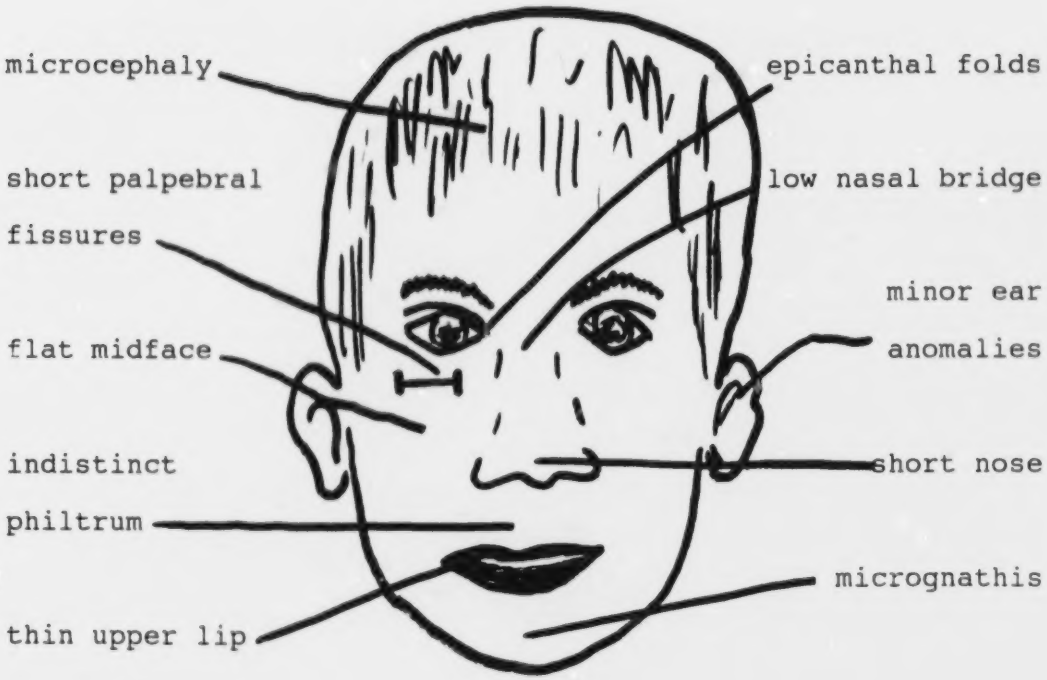
The problem is broad and runs through many generations. The solutions are hard, but are there. Care for the F.A.S. population must be provided throughout life. Prevention for youth must be strong and constant. Treatment centers are necessary but should not become revolving doors. Aftercare programs for individuals and their families in traditional settings with traditional teaching must be established. This cannot be done without total tribal support. If the locus of control is not returned to the tribe and to individuals the alcoholic problem will be the death of Indian Country (Thurman 1990). F.A.S. is a forgotten area of alcoholism impact for many tragic adolescents and adults. It does not go away for them. At the present time it only grows in severity for Native Americans and for society at large.

Which right is more important, a woman's right to drink or an unborn child's right to a healthy life? Ultimately society must care for F.A.S. children and society allows this to continue. These are very threatening thoughts to those who exist on block grants. Bills are being introduced

into Congress to allow force in protecting the child. This could also turn into a forced abortion or sterilization issue. Positive interventions, like counseling and treatment which is accessible, are necessary. With the rising costs of education and dwindling funds, what will schools systems do with large populations of these children who now are placed in Mentally Retarded or Learning Disabled programs? No one has found an educational method that moves these individuals from childhood to adulthood (Wescott 1990).

Wescott says that Native Americans traditionally have deep compassion for each other. This can be used to encourage all pregnant women to refrain from drinking and to make them comfortable in social settings without drinking. This must be done and can be done now by communities without funds and buildings, or buildings will be built later to care for what is left of the tribes and the ravaged individuals alcohol has produced.

Features of Fetal Alcohol Syndrome



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